

I am submitting this testimony in support of Raised Bill Number 918- An Act Concerning the Provision of Services to Individuals with Intellectual Disability.

This bill would require the Department of Developmental Services (DDS) to plan and provide services to individuals with intellectual disability who are eligible and in need of services, including individuals on the waiting list by July 1, 2017. The services include; community-based residential placements, respite care, emergency care, day programs, vocational services and in-home supports. The bill also requires DDS to identify the additional staff and cost required to provide the services.

The DDS budget has been cut by more than \$43 million since November 2012. Every budget, mitigation plan and ordered rescission since then has continued to reduce funds for community providers, who support individuals with intellectual disability and their families. These cuts have continued in the context of 30 years of chronic underfunding for the same community providers supported by DDS to care for our most vulnerable citizens. It's time to establish a statewide plan to prioritize funding for individuals with intellectual disability and their families, community providers and direct care workers.

Our son Angel, who is 20 ½ years old, has Autism and Moderate Mental Retardation. In June 2015, our son will be graduating from CREC River Street School, in Windsor, CT. This is a school designed to help and educate individuals with Autism and Behavior issues. He recently transitioned into a Group Home and we have been diligently looking for Day Support Programming for him to enter upon his graduation. We have recently learned that due to budget cuts that this service may not be available to him upon his graduation. We are writing to please urge you to stop this from happening. Over the years our son has made significant progress due to the services he has received through the Department of Developmental Services and we want him to continue to be successful in his adult life.

At the age of 8, he became involved with what used to be DMR (Department of Mental Retardation) and now DDS (Department of Developmental Services). As my son became older and reached puberty his behaviors began to escalate. His self-injurious behaviors increased and he became extremely aggressive towards others at home and school. We tried to manage his behaviors the best way we could, however by the time he was 15 he had been hospitalized twice due to aggressive behaviors towards me, his sisters, and other family members. His sisters and other family members were afraid to be near him as there were no known antecedents for his aggressive behaviors. On May 25, 2009, my son was admitted to the hospital for a second time and it was at that point I realized I needed more help for my son. My son was hospitalized for 9 weeks at Hampstead Hospital in New Hampshire because Connecticut does not have any Hospitals that specialize in dealing with individuals with Autism and extreme aggressive behaviors. It was during those nine weeks that I advocated and fought for my son to get Individualized Home and Clinical Support because the hospital would not discharge him unless services were put in place for him at home. It was at that time that we entered DDS Voluntary Services Program (VSP) and received the help I needed for my son. My son was discharged from Hampstead Hospital on July 31, 2009. My son was had been in an out of state hospital for nine weeks; I traveled every weekend for those nine weeks to be close to my son. I was a single mother at that time, not only of Angel, but of three children, working full time trying to keep things together. The doctors, psychiatrist, and behaviorist worked diligently to find the right medication regimen to help manage his aggressive and self injurious behaviors and develop an appropriate behavior plan for him. Since his discharge on July 31, 2009, he has not had to be inpatient for aggressive or self injurious behaviors. This is due to the services and supports we received through the DDS Voluntary Services Program. We worked in collaboration with an agency and received the in home clinical and individualized support my son needed, so that he could be successful. Upon his discharge from Hampstead, he was also accepted to CREC River Street School, a school that specialized in working with individuals with Autism and behavior issues. The West Hartford Public School system tried diligently before his hospitalization to create and develop services for him, however his needs were too great and he had to be outplaced to a more appropriate

educational setting.

When DDS VSP Individualized Home Services commenced, it was a battle, Angel was resistant, he was still aggressive and had self injurious behaviors. However, the in home clinical and in home support staff never gave up, they worked hard to help our him as they knew he had the potential to do better, and he has. It was during this time I met my husband. I was lucky to find a husband who works with individuals with special needs and considers my children as his own. With having a husband who works in the field and the extensive support we received through DDS, Angel's aggressive behaviors decreased significantly, he has become more verbal, and his sisters and other family members are no longer afraid to be near him. Our son is not the same person he was when he was admitted to Hampstead Hospital in May 25, 2009. In the past 6 years of being part of DDS VSP, our son has made significant progress and that is thanks to the services he received through DDS. I recognize that not many families have someone living in their home who works in the field and do not have the skills to deal with an individual with aggressive behaviors. This is why DDS voluntary services programming is so crucial, as even with all the supports we had it was and continues to be struggle having a child with Autism and aggressive behaviors.

For the past year, my husband and I have thought a lot about what our next steps will be for our son as he transitions to adulthood. We looked at every option there was and in the end we made the difficult decision to transition our son into a Group Home, which I like to call his Forever Home. With the help of his exceptional DDS case manager, Maria Rosado, we were able to successfully transition our son into his forever home on 12/8/14. This was not an easy task as our son is an 8 on his level of need at both home and school, which is the highest level of need an individual can be identified on the DDS level of need assessment. Transitioning him into his forever home was not an easy decision for us by any means, we love our son dearly and never imagined him being anywhere, but with us. However, the reality is, someday we will not be here and we need to ensure that when that day comes, our son is placed appropriately and has all the services he needs in order to continue to be successful in life. There is no one else in our family who can physically care for or advocate for what is in his best interest. It would not be fair of me to ask his older and twin sister to physically take care of him when we are no longer here, as they deserve to have a life of their own. All of their lives they have dealt with and been witness to his aggressive tendencies. They have also undergone the daily struggles and stressors of life with a person that has Autism, who also has aggressive and self injurious behaviors.

Next month, our son will be 21 years old and in June 2015 he will be graduating from CREC River Street School. Upon graduation, he will require an Individualized Day Program so that he can continue to be successful in life. Since last summer, my husband and I have visited many agencies in order to find one that will be able to provide appropriate Day Support Programming for our son. We have narrowed our list down to four agencies that have the appropriate services our son would need upon graduation. Now we are being told that there might be no funding available for our son or other individuals like him for Day Programming Services. What is going to happen to our son and other individuals like him? These individuals are our most vulnerable population as they cannot advocate for themselves, they have no voice. We, as their parents and advocates, are their voice. These types of services, such as Individualized Day Support Programs, are crucial to individuals like our son to be successful in life. I plead for your support to stop the budget cuts from eliminating the funding needed for these Day Programs and other DDS programs. Our children need these programs in order to continue to be successful in their adult life. Thank you.

Sincerely,
Jellyzanee & Juan Carrion
30 Madsen Road
West Hartford, CT 06110-2555